

# Insights into Pain: A Review of Qualitative Research

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## SUMMARY POINTS

- Qualitative research exposes and explores important aspects of the pain experience that are inaccessible to other approaches.
- Qualitative work adopts a different epistemological and ontological perspective to quantitative work.
- Qualitative research is not well established in the field of pain, but is growing.
- More interpretative engagement with qualitative data is required.

## Introduction

Pain is an experience which is ubiquitous yet at the same time quintessentially subjective. It is influenced by an incredible array of contextual factors including those in the spiritual, social, cultural, cognitive, emotional and bio-medical domains. It is private and is often suppressed, concealed or exaggerated according to the setting. This means that drawing inferences based on the behaviour of the person with pain is problematic. This is nothing new to pain researchers and is perhaps part of the reason so many people feel drawn to study it, either to explain the “puzzle” of pain<sup>1</sup>, or rise to the “challenge” of pain<sup>2</sup>.

Pain researchers are constantly trying to develop more creative and effective ways of capturing and studying pain. However the very nature of pain (subjective, dynamic and multi-dimensional) means it is extremely difficult to quantify. Qualitative approaches can help with this endeavour because

*“.....the questions they [the unpredictabilities of pain] provoke demand explanations that cannot be answered simply by conventional biomedical evidence.”<sup>3</sup>*

Qualitative approaches attempt to explore the personal experience of a phenomena and access the “insider’s experience”<sup>4</sup> and adopt a different ontological position to quantitative work. In other words, qualitative work does not set out to discover a ‘real’ or irreducible ‘thing’ that is stable enough to be generalized to other populations of people, but articulates the many and plural meanings that might be attached to it. In the main, it acknowledges a real world, and a shared one, but presumes that this can only be accessed through a process of appraisal and interpretation which is situated within the person’s spiritual-cultural-social-personal setting<sup>5</sup>. Although qualitative

approaches share much in common with one another, they can differ on critical theoretical or ontological points and certain approaches consider themselves to be as different to other qualitative approaches as they are to quantitative ones.

The aim of this paper is to present a summary of the empirical qualitative work on pain that has been published over the last 10 years using particular articles as exemplars of the substantive themes we identified in our analysis of the papers we reviewed<sup>6</sup>.

In evaluating the papers included in our review we drew upon criteria<sup>11,12,13</sup> which included themes such as sensitivity to context, rigour, transparency, internal coherence, independent audit, independent researcher, and presentation of data/evidence. Depth of analysis was also considered and the studies foregrounded in this review were those that went beyond a simple description of the participants’ experience to interpret the deeper meanings in the data and present a sufficient amount of it for the reader to assess their argument.

## Review Method

A search using Web of Science (WoS) databases from 1998-2008 was conducted using the terms “pain” and “qualitative” and (“interview” or “focus group” or “observation”). This produced 208 articles of which 105 were rejected as pain was not the principal focus of the study. We noticed that some papers with which we were familiar had not been identified in the WoS search; we therefore also searched particular journals for papers meeting our criteria including Social Science and Medicine, Sociology of Health and Illness, Pain, European Journal of Pain. In addition, the reference lists of the selected articles were scoured for any other articles which might

<sup>a</sup> For more detail, please see Ashworth<sup>5</sup> for an excellent summary of the conceptual foundations of qualitative psychology and also Murray and Chamberlain<sup>6</sup> for a review of many and varied approaches that have been adopted in qualitative health psychology. <sup>b</sup> Some excellent earlier qualitative work on pain by authors such as Kotarba<sup>7</sup>, Charmaz<sup>8</sup>, Bury<sup>9</sup> and Kugelmann<sup>10</sup> have, as a result not been included, although some reference is made to Charmaz’ work.

have been missed and this produced another 10 articles. A further 16 papers were rejected as on reading they were more theoretical/methodological than empirical. This left 97 papers which were reviewed and categorised into the following themes:

- Understanding the experience of pain (41 papers)
- Process of managing a condition and seeking help (48 papers)
- Preliminary development of quantitative measures (8 papers)

This review excludes the third theme because the studies that used qualitative methods as the initial stage of the development of a questionnaire tended to include it as a small part of a bigger study and very little data or detail was available to interrogate beyond the theme titles that emerged. Prior to presenting the two themes we have included, we present a general overview of the papers included.

Our initial reaction to reading the body of work was one of mild disappointment as the recent explosion of interest in qualitative research was not too apparent. Furthermore the majority of studies confined themselves to a simple description of the data, rather than a deeper interpretative engagement with it, that would yield a rich idiographic account of the participants' experience. However there was plenty of good work that made a palpable and complementary contribution to our understanding of pain. The key issues to arise from our initial reading of the papers were as follows:

1. Although not something which was explicitly commented on by the authors of the articles reviewed, it was apparent that many studies struggled with quite prohibitive word length limits and as a result had to be quite economical with their analysis. Whilst this promoted concise writing, it also limited the richness of the data that could be presented or the number of the themes that were outlined.
2. Our search terms deliberately did not specify "acute" or "chronic" pain; the intention was to be as inclusive as possible. However, the majority of articles included in our review focused upon chronic rather than acute pain. So many different types of pain were studied it would be impossible to list them all here, however, the types ranged from musculo-skeletal pain which was the most commonly studied; cancer pain<sup>14-16</sup>; post operative pain<sup>17,18</sup>; and chest pain<sup>19</sup>.
3. A wide variety of methods were employed (including, interviews, observation, focus groups, diaries).
4. There was wide variation in the mode of analysis chosen, including content analysis, thematic analysis, spradley's domain analysis, framework approach, constant comparative method, grounded theory, interpretative phenomenological analysis, microanalysis, Giorgi's phenomenological analysis

and discourse analysis. Other analytic processes were also used but not given a name nor described in detail.

5. Unfortunately the method section was frequently neglected and as a consequence, it was often difficult to understand quite what the researcher did to reach their conclusion.
6. Often the emergent themes related to the participants' experience of being a person-in-pain and the meaning that had for them in a social as well as a physical context.

Given the limitation of space it is not possible to summarise each of the 89 papers we included in our review. Instead, we have engaged in a process of thematic analysis in order to identify the most commonly reported issues. In presenting our findings, we refer to particular studies, and include a selection of representative quotes as a means of demonstrating the issue being presented. Our review has therefore been summarised by collating the studies into two broad but related super-ordinate themes; the lived experience of a wide range of different pains and the personal experience of seeking help for pain.

### Lived Experience of a Range of Pains

A range of studies focused on the lived experience of a number of pain conditions. As mentioned earlier in this paper, chronic pain was the most commonly researched type of pain. Of prime importance was the feeling expressed by patients that others did not recognise the practical and emotional issues that participants experienced as they dealt with their pain condition in the context of their 'normal everyday' lives. In particular, the participants' accounts showed that they often shared: feelings of confusion and worry; an ongoing assault on the self by the pain, and the social and cultural unpleasantness of living with pain.

### Confusion and Worry

Despite usually living with their pain for many years the participants were often confused about their pain<sup>20</sup> and, as they couldn't make sense of it, were worried about their future. A recent study articulated this very well and focused on the nature of the despair related to pain<sup>21</sup>. This was illustrated with quotes like:

*"It is there all the time...it's just, I just want to know what...what the pain is.."*

*"you know, coping with pain is one thing, but coping with the psychological thing is really hard"*

*"surely it can only get worse..."*

## Assault on the Self

Several studies identified how the participants struggled to maintain a valued sense of self or identity as they lived with their pain over time<sup>22</sup>, for example focusing on how difficult it was to maintain any sense of self-regard or dignity when in pain<sup>23,24</sup>, or describing the experience of progress on a rehabilitation programme as, in part, the retrieval of a sense of self-respect and a shift away from a sense of shame<sup>25</sup>. One study looked at the self in particular and described how different selves emerged over time in chronic pain. This was often a problematic process as the emergent contemporary selves could be considered as “spurious” or “entrapped” and not helpful in the process of adjustment toward better pain management<sup>26</sup>. Much earlier, Charmaz<sup>8</sup> described a similar process where pain produced a “fundamental loss of self” whereby the self could become supplanted by an array of contemporary “fictional selves” that were, as in the Hellstrom study, similarly unhelpful. The participants’ experiences of the self when in pain often lead them to reject their contemporary self as “not me”: neither preferred nor valued<sup>22</sup>. Rejecting their contemporary sense of self was an incoherent and confusing experience which also rejected any notion of an acceptance or accommodation to pain:

*“It’s not who I am its just who I am if you know what I mean, it’s not really me, I get like that and I know like, you’re being mean now but I can’t help it. It’s the pain, it’s me, but it is me, me doing it but not me”*

## Social Unpleasantness

Several studies described in detail how difficult it was for the participants to relate to others. For example, participants worried about being believed and as a consequence, often concealed their private experience of pain or withdrew socially<sup>20</sup>. Others described how the fear of being judged compelled participants’ to keep silent and as a result, something that had made such a profound change in their lives was, paradoxically, often never spoken about and a sense of loneliness and alienation accompanied the pain<sup>27</sup>. Pain appeared to stifle communication;

*“some people must think I whinge and I try and when they say ‘how are you’ I say ‘fine’”*

Similar accounts were given in a study<sup>22</sup> which highlighted the levels of fear related to the anticipated judgements of others:

*“I think about it all the time – what do other people think of me – it’s the mental battle that’s the hardest”*

*“When are they going to round us up and take us away”*

Alongside their own uncertainties, the participants in several studies worried about the ignorance of others given the invisibility of their pain, for example:

*“but no one sees what I’m feeling, that I’m always tired and don’t get enough sleep, that’s something they can’t do anything about.”<sup>28</sup>*

*“If I had a broken leg or something, then he could see it and he could understand it, but because its internal. I mean I say to him ‘Oh I’m in a lot of pain’ or ‘I’ve had a bad day’ and nothing is said”<sup>29</sup>*

The problems of communicating pain and relating to others were central to several studies that showed how the participants’ family and social roles were affected by their pain and either restructured, renegotiated or undermined in some way. For example describing the problems of maintaining ‘normal’ family and social roles in the face of change due to pain<sup>28,30,31</sup>. The importance to the participants of feeling that they lead a normal (i.e. pre-pain) lifestyle was prominent in their accounts and again, could be problematic if it was considered more important than adjusting to the presence of pain. The tension inherent in living with pain between the participants’ need for emotional support and the retention of some degree of independence and autonomy was described by participants in detail<sup>29,32</sup>.

## Personal Experience of Seeking Help for Pain

A range of studies focused on the experience of being a patient in pain. The sub-themes related to it mirrored those described above to some degree; particularly the fear of judgement, difficulty with communicating and sense of incoherence. The experience of being a patient was often described as unpleasant or punitive and involved feelings of having to struggle to be taken seriously and treated with dignity<sup>33</sup>. Often the service they accessed was an exclusively biomedical one where no time or staff were allocated to focus on anything non-medical and given the difficulties described above of living with the distress of pain, it is perhaps not surprising that a sense of neglect and antagonism should emerge in the clinical setting. One study<sup>27</sup> gave a strong account of the problems involved:

*“When you have been in pain for a long time, you don’t actually see the consultant. You wait for ages and ages and ages and you come out feeling totally baffled really. He [the doctor] doesn’t really seem to understand your problem, and you feel like bursting into tears, you have wasted such a lot of time and energy.... You don’t feel like you are being treated as a person at all.”*

When interviewed themselves, health professional staff did not express a critical view of pain sufferers but described a similar profile of distress and in particular, shared their patients’ sense of hopelessness as they struggled to find a way to help their patients<sup>34,35</sup>.

Other studies gave positive accounts of the participants’ experiences as patients, which often contextualised the service (both primary and secondary services) as an interpersonal relationship. When describing a successful therapeutic encounter the participants described feeling a sense of security and a feeling of belonging<sup>36</sup> or a felt sense of empathy and engagement<sup>29</sup>. Being believed in a manner that enabled one participant to understand their pain as a non-psychiatric disorder

was helpful and enabled them to understand their pain experience in a different moral context:

“that was the first time somebody had said ‘it wasn’t your fault’....I knew then it wasn’t in my head...”<sup>29</sup>

Similarly, being offered a feeling of mutual understanding and recognition by staff<sup>37,38,39</sup> enabled participants to move toward an acceptance of their pain as something that was not a source of stigma.

## Discussion

The purpose of this paper was to present a summary of the empirical qualitative work on pain that has been published in the last ten years. In order to be inclusive in our search strategy we used the term “pain”. We found that the majority of the papers included in our review focused on different types of chronic pain, with very few focusing on acute pain. A limitation of our review is therefore that our findings are biased towards the chronic pain field and therefore of less relevance to the study of acute pain.

We categorised the papers that were included in our review as focusing on one of two broad themes; that of the ‘lived experience of pain’, and that of ‘the personal experience of seeking help for pain’. The way in which pain is experienced and managed will of course be influenced by a number of important variables, including whether or not the cause of the pain is benign, whether there is a known or unknown diagnosis for the pain, as well as the age and gender of the person experiencing the pain. Exploring the influence of these variables was beyond the scope of this paper. Nevertheless, the qualitative studies that have been reviewed here showed how the subjective or personal experience of pain extended the unpleasantness of pain beyond the sensory or emotional aspects to include the interpersonal, social and cultural domains. The participants gave extensive accounts of their distress and talked about how they struggled to maintain a stable, coherent or valued sense of either being a person or being treated like a person.

The extent to which the qualitative findings we have summarised reflect those reported in the quantitative literature, and vice versa, is an issue which would benefit from further systematic study. For example, themes we had considered to be well established in the quantitative literature (such as acceptance, fear avoidance and catastrophising) with few exceptions (e.g. Walker, Sofaer and Holloway, 2006)<sup>40</sup> were not referred to in the qualitative studies we reviewed. Whilst this interpretation is more anecdotal than one which we can currently support with evidence, we argue that it is something which merits further systematic research. Indeed, identifying the similarities and differences between the focus and findings of qualitative and quantitative work in the field of pain would perhaps encourage more researchers from both methodological approaches to draw from one another’s perspectives.

In terms of the practical implications of our findings, we identify three issues of importance. First, we hope that more empirical qualitative pain research will be carried out in the future. In particular, we feel it would be helpful if qualitative researchers could build on their work. We found that it was rare for any one researcher to accumulate a substantial body of work that enabled them to develop their arguments.

Second, we would like to encourage more researchers to go beyond description in their analysis and attempt a more interpretative engagement with their data (of course the descriptive and the interpretative can co-exist in the same study). We recognise that the tendency to lean towards description might well be a consequence of the constraints strict word limits can impose. Whilst we did not interview the authors of the papers included in our review, it was apparent that in order to comply with journal guidelines parsimony was employed. As qualitative researchers ourselves, we too have battled with the dilemma of how to present findings in sufficient detail. Perhaps there is a need to explicitly identify the barriers to conducting and publishing good quality qualitative pain research.

Third, although we did not formally rate the quality of the articles we included in our review, we noticed that more rigour in describing the methods used is required. The method section of many of the papers was an area we felt was neglected. This made it difficult to discern how the authors had reached their conclusions. A more transparent attention to the method section would improve the reporting of empirical qualitative work. We also noticed that there was a neglect of single-case design, longitudinal or mixed method studies, all of which could make a valuable contribution to the field.

## Conclusion

In this paper we have provided a summary of qualitative empirical work that has been published over the last ten years. This research has focussed both on the experience and process of managing pain. We demonstrated that people who live with pain also live with confusion and worry as they try to make sense of what they feel is an uncertain future. People living with pain spoke of the struggle to maintain a sense of identity whilst dealing with the additional problems of maintaining normal social and familial roles. The experience of living with pain was coloured by the process of seeking help to manage their pain. There was a strong sense of hopelessness and distress from both those living with pain, and the health professionals providing support. Thus, as we noted above, qualitative research demonstrates that pain is something which extends beyond the sensory and cognitive domains, to foreground the destructiveness of the interpersonal, social and cultural factors involved.

In our discussion we highlighted a number of limitations both of this review and of the current shape of qualitative research in the field of pain. In light of these limitations we make three suggestions. There is a need for:

- A formal systematic review of qualitative research into chronic versus acute pain.
- A theoretical paper that attempts to evaluate the similarities and discrepancies between qualitative and quantitative empirical pain research.
- The identification of barriers to the conduct and publication of good quality qualitative pain research.

Until these suggestions are implemented, we conclude that whilst qualitative work is far from being well established in pain research, it shows promise. It exposes and explores important aspects of the pain experience that are inaccessible to other approaches. It is different to quantitative study and so will never replace it..... but it will enrich it.

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